

## General

### Title

Sickle cell disease (SCD): percentage of children in a state between the ages of 3 months and 5 years diagnosed with SCD who received appropriate antibiotic prophylaxis for at least 300 days during the measurement year.

### Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate antibiotic prophylaxis for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2013 Dec 13. 43 p. [15 references]

## Measure Domain

### Primary Measure Domain

Population Health Quality Measures: Population Process

### Secondary Measure Domain

Does not apply to this measure

## Brief Abstract

### Description

This measure is used to assess the percentage of children in a state between the ages of 3 months and 5 years diagnosed with sickle cell disease (SCD) who received appropriate antibiotic prophylaxis for at least 300 days during the measurement year.

### Rationale

Spleen damage is a common and crucial characteristic of sickle cell disease (SCD): a damaged spleen cannot effectively clear bacteria from the blood, leaving SCD patients, particularly young children, highly susceptible to infection. Children with SCD experience rates of infection caused by the bacterium *Streptococcus pneumoniae* 30 to 100 times more frequently than children without SCD. Pneumococcal vaccines are of limited effectiveness in this age group because of lowered antibody response. However,

twice-daily doses of an antibiotic sharply reduce the incidence of *S. pneumoniae* disease in children with SCD.

Studies have shown that children with SCD who are enrolled in Medicaid frequently are not dispensed antibiotics soon enough or in sufficient quantities to cover ongoing twice-daily use. Sometimes these children receive no antibiotics at all, even though this simple preventive medication greatly reduces their risk of contracting debilitating and often deadly infections. Clinical guidelines and the results of randomized controlled trials indicate that providers should prescribe appropriate antibiotic prophylaxis to children with SCD who are under 5 years of age. There are no existing quality measures for antibiotic prophylaxis in children with SCD.

Prompt initiation and consistent use of antibiotics in young children with SCD increases survival rates through the prevention of overwhelming bacterial infections (National Heart, Lung and Blood Institute [NHLBI], 2002). Because sickle cells obstruct blood flow to the spleen, splenic function is compromised, leading to susceptibility to bacterial infections (NHLBI, 2002). Meningitis, pneumonia, and sepsis are major causes of death in children with SCD, and pneumococcal sepsis is known to progress from the onset of fever to death in fewer than 12 hours (Gaston et al., 1986). Given that the highest rate of infection occurs in children with SCD under the age of 3 years (Hirst & Owusu-Ofori, 2010), NHLBI guidelines recommend that infants identified through newborn screening (NBS) as having SCD should be started on daily prophylactic penicillin as early as possible and remain on preventive antibiotics until age 5 years (2002).

## Evidence for Rationale

Gaston MH, Verter JI, Woods G, Pegelow C, Kelleher J, Presbury G, Zarkowsky H, Vichinsky E, Iyer R, Lobel JS, et al. Prophylaxis with oral penicillin in children with sickle cell anemia. A randomized trial. *N Engl J Med*. 1986 Jun 19;314(25):1593-9. [PubMed](#)

Hirst C, Owusu-Ofori S. Prophylactic antibiotics for preventing pneumococcal infection in children with sickle cell disease. *Cochrane Database Syst Rev*. 2012;9:CD003427. [PubMed](#)

National Heart, Lung and Blood Institute (NHLBI). The management of sickle cell disease. 4th ed. Bethesda (MD): National Institutes of Health, National Heart, Lung and Blood Institute, Division of Blood Diseases and Resources; 2002 Jun. 188 p.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate antibiotic prophylaxis for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2013 Dec 13. 43 p. [15 references]

## Primary Health Components

Sickle cell disease (SCD); antibiotic prophylaxis; children

## Denominator Description

The eligible population consists of children in a state aged 90 days or older on January 1 of the measurement year but younger than 5 years on December 31 of the measurement year who are continuously enrolled in Medicaid and received an appropriate sickle cell disease (SCD)-related International Classification of Diseases, Ninth Revision (ICD-9) code on three or more separate health care encounters during the measurement year (see the related "Denominator Inclusions/Exclusions" field).

## Numerator Description

The number of eligible children in a state who received appropriate antibiotic prophylaxis for at least 300 days, as determined by administrative record review (see the related "Numerator Inclusions/Exclusions" field)

## Evidence Supporting the Measure

### Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

A systematic review of the clinical research literature (e.g., Cochrane Review)

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

### Additional Information Supporting Need for the Measure

#### *Sickle Cell Disease Prevalence and Incidence*

Sickle cell disease (SCD) is one of the most common genetic disorders in the United States (Kavanagh et al., 2011). The National Heart, Lung and Blood Institute (NHLBI) (2002) estimates that 2,000 infants are born with SCD in the United States (U.S.) each year. SCD affects 70,000 to 100,000 children and adults in the United States, predominantly those of African and Hispanic descent (Hassell, 2010).

#### *Sickle Cell Disease Pathology and Severity*

Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with SCD (Kavanagh et al., 2011).

#### *Sickle Cell Disease Burden in Daily Life*

The effect of SCD on children and families is significant: severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, sleep, and social activities (Lemanek, Ranalli, & Lukens, 2009; Alvim et al., 2005). Although medical management of SCD continues to improve over time, 196 U.S. children died from SCD-related causes between 1999 and 2002 (Yanni et al., 2009).

#### *Sickle Cell Disease Cost*

In a study of health care utilization among low income children with SCD between 2004 and 2007, 27% of these children required inpatient hospitalization and 39% used emergency care during a year. Of these children, 63% averaged one well-child visit per year and 10% had at least one outpatient visit with a specialist (Raphael et al., 2009). Patients with SCD use many parts of the health care system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were \$23,000 for children with private insurance and \$18,200 for children enrolled in Medicaid (HCUPnet, Healthcare Cost and Utilization Project, 2012). Kauf et al. (2009) estimate the lifetime cost of health care per patient with SCD to be approximately \$460,000.

#### *Performance Gap – Prophylactic Antibiotics*

In one study, children with SCD and enrolled in Medicaid were dispensed, on average, enough prophylactic medication to cover only 40% of the study year (Sox et al., 2003). Approximately 22% of children

received medication to cover more than 270 days, but about 43% received 90 days of medication or less, and 10% of children received no antibiotics at all. These findings show a clear performance gap in the daily provision of prophylactic antibiotics to children with SCD.

In a study of 248 pediatricians regarding their knowledge and adherence to sickle cell guidelines, 97% of pediatricians answered correctly questions about the necessity of antibiotics for children with SCD, yet only 66% of pediatricians reported prescribing prophylactic antibiotics for 100% of their patients with SCD (Wurst & Sleath, 2004). Although pediatricians understand the necessity of prophylactic antibiotics for children with SCD, they do not always prescribe them as recommended.

## Evidence for Additional Information Supporting Need for the Measure

Alvim RC, Viana MB, Pires MA, Franklin HM, Paula MJ, Brito AC, Oliveira TF, Rezende PV. Inefficacy of piracetam in the prevention of painful crises in children and adolescents with sickle cell disease. *Acta Haematol.* 2005;113(4):228-33. [PubMed](#)

Hassell KL. Population estimates of sickle cell disease in the U.S. *Am J Prev Med.* 2010 Apr;38(4 Suppl):S512-21. [PubMed](#)

HCUPnet. Healthcare Cost and Utilization Project. [Web site]. Rockville (MD): Agency for Healthcare Research and Quality; 2006-2009

Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. *Am J Hematol.* 2009 Jun;84(6):323-7. [PubMed](#)

Kavanagh PL, Sprinz PG, Vinci SR, Bauchner H, Wang CJ. Management of children with sickle cell disease: a comprehensive review of the literature. *Pediatrics.* 2011 Dec;128(6):e1552-74.

Lemanek KL, Ranalli M, Lukens C. A randomized controlled trial of massage therapy in children with sickle cell disease. *J Pediatr Psychol.* 2009 Nov-Dec;34(10):1091-6.

National Heart, Lung and Blood Institute (NHLBI). The management of sickle cell disease. 4th ed. Bethesda (MD): National Institutes of Health, National Heart, Lung and Blood Institute, Division of Blood Diseases and Resources; 2002 Jun. 188 p.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate antibiotic prophylaxis for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2013 Dec 13. 43 p. [15 references]

Raphael JL, Dietrich CL, Whitmire D, Mahoney DH, Mueller BU, Giardino AP. Healthcare utilization and expenditures for low income children with sickle cell disease. *Pediatr Blood Cancer.* 2009 Feb;52(2):263-7. [PubMed](#)

Sox CM, Cooper WO, Koepsell TD, DiGiuseppe DL, Christakis DA. Provision of pneumococcal prophylaxis for publicly insured children with sickle cell disease. *JAMA.* 2003 Aug 27;290(8):1057-61. [PubMed](#)

Steinberg MH. Management of sickle cell disease. *N Engl J Med.* 1999 Apr 1;340(13):1021-30. [PubMed](#)

Wurst KE, Sleath BL. Physician knowledge and adherence to prescribing antibiotic prophylaxis for sickle cell disease. *Int J Qual Health Care.* 2004 Jun;16(3):245-51. [PubMed](#)

## Extent of Measure Testing

### Reliability

*Data/Sample.* Our sample consisted of six states with a moderate-to-high prevalence of sickle cell disease (SCD): Florida, Illinois, Louisiana, Michigan, South Carolina, and Texas. Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) tested this measure using a sample drawn from 5 consecutive years of Medicaid Analytic eXtract (MAX) administrative claims data provided by the Centers for Medicare & Medicaid Services (CMS). The measure was implemented using MAX data for each state to evaluate consistency of results for the most current 5-year period for which MAX data were available. This measure was tested as specified, which requires the assessment among the entire population of children with SCD between the ages of 3 months and 5 years within the measurement year. This measure does not involve sampling within states; all SCD cases are included in the measure specification.

For two states (Michigan and Illinois) additional samples of administrative claims were obtained directly from the respective state Medicaid programs to evaluate the reliability of using MAX administrative data for this measure. In addition, we conducted a medical record review in Michigan to evaluate the coding reliability and accuracy of Medicaid administrative claims for antibiotic prescriptions.

Refer to the original measure documentation for additional testing results.

### Validity

*Face Validity.* Face validity is the degree to which the measure construct characterizes the concept being assessed. The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by Q-METRIC. The Q-METRIC expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans.

The Q-METRIC expert panel concluded that this measure has a very high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was among the most highly rated, receiving an average score of 8.5 (with 9 as the highest possible score).

*Validity of Coded Data.* This measure is based on administrative claims data; therefore, the validity of the coded data reported in Medicaid claims was assessed through a medical record review. A subset of SCD cases was identified from Michigan Medicaid claims data, and a chart audit was conducted by trained medical record abstractors to compare administrative data with the corresponding medical record. We conducted a medical chart audit for cases identified in Michigan Medicaid claims for care provided at the three largest centers serving SCD patients in Michigan during 2012: Children's Hospital of Michigan (CHM, Detroit), Hurley Medical Center (HMC, Flint), and the University of Michigan Hospital and Health System (UMHS, Ann Arbor).

Our review indicates that the Medicaid administrative claims have a high degree of agreement with antibiotic prescriptions recorded in medical records abstracted from CHM, HMC, and UMHS. We considered claims within 1 month of the prescription date to accommodate for lags between the date in the medical record indicating that the antibiotic was prescribed versus the actual prescription fill date that is recorded in claims. Among the 35 SCD cases eligible for review for this measure, 34 (97%) of cases identified through medical record review were successfully matched with Michigan Medicaid administrative claims

data (refer to Table 6 in the original measure documentation); the one case that could not be matched was not enrolled in Medicaid (i.e., did not have a Medicaid ID). Sensitivity was high for identifying antibiotic prescription events using Medicaid administrative claims data; 30/34 (88%) antibiotic prescriptions from the medical record review had a Medicaid administrative claim for an antibiotic within 1 month of the prescription date in the medical record. The positive predictive value of a Medicaid claim for an antibiotic prescription event was 100% (30/30). All eligible cases identified in the medical records had an antibiotic prescription recorded; consequently, the specificity could not be calculated (i.e., undefined due to division by zero).

## Evidence for Extent of Measure Testing

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate antibiotic prophylaxis for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2013 Dec 13. 43 p. [15 references]

## State of Use of the Measure

### State of Use

Current routine use

### Current Use

not defined yet

## Application of the Measure in its Current Use

### Measurement Setting

Ambulatory/Office-based Care

Community Health Care

Hospital Inpatient

Hospital Outpatient

Regional, County, or City Public Health Programs

State/Provincial Public Health Programs

### Type of Care Coordination

Coordination between providers and community

Coordination between providers and patient/caregiver

### Professionals Involved in Delivery of Health Services

not defined yet

## Least Aggregated Level of Services Delivery Addressed

State/Provincial

## Statement of Acceptable Minimum Sample Size

Does not apply to this measure

## Target Population Age

Age 3 months to 5 years

## Target Population Gender

Either male or female

## National Framework for Public Health Quality

### Public Health Aims for Quality

Population-centered

## National Strategy for Quality Improvement in Health Care

### National Quality Strategy Aim

Healthy People/Healthy Communities

### National Quality Strategy Priority

Effective Communication and Care Coordination

Health and Well-being of Communities

Prevention and Treatment of Leading Causes of Mortality

## Institute of Medicine (IOM) National Health Care Quality Report Categories

### IOM Care Need

Getting Better

Living with Illness

Staying Healthy

## IOM Domain

Effectiveness

## Data Collection for the Measure

### Case Finding Period

The measurement year

### Denominator Sampling Frame

Geographically defined

### Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

Patient/Individual (Consumer) Characteristic

### Denominator Time Window

not defined yet

### Denominator Inclusions/Exclusions

#### Inclusions

The eligible population consists of children in a state aged 90 days or older on January 1 of the measurement year but younger than 5 years on December 31 of the measurement year who are continuously enrolled in Medicaid and received an appropriate sickle cell disease (SCD)-related International Classification of Diseases, Ninth Revision (ICD-9) code on three or more separate health care encounters during the measurement year (refer to Table 1 of the original measure documentation). The designated ICD-9 codes are for sickle cell anemia, which is the most severe form of SCD.

Note: *Intake Period*: January 1 of the measurement year through December 31 of the measurement year.

#### Exclusions

Claims in the administrative records for any of the sickle cell disease variants listed in Table 3 of the original measure documentation do not count toward the "three or more separate healthcare encounters" criteria.

### Exclusions/Exceptions

not defined yet

### Numerator Inclusions/Exclusions



## Inclusions

The number of eligible children in a state who received appropriate antibiotic prophylaxis\* for at least 300 days, as determined by administrative record review

*\*Antibiotic Prophylaxis:* Any type of penicillin or any type of erythromycin, two doses daily, for the full 300 days (refer to Table 3-A in the original measure documentation). Evidence of antibiotic prophylaxis is determined through administrative records for pharmacy prescriptions filled.

## Exclusions

Unspecified

## Numerator Search Strategy

Fixed time period or point in time

## Data Source

Administrative clinical data

## Type of Health State

Does not apply to this measure

## Instruments Used and/or Associated with the Measure

Unspecified

## Computation of the Measure

## Measure Specifies Disaggregation

Does not apply to this measure

## Scoring

Rate/Proportion

## Interpretation of Score

Desired value is a higher score

## Allowance for Patient or Population Factors

not defined yet

## Standard of Comparison

not defined yet

# Identifying Information

## Original Title

Appropriate antibiotic prophylaxis for children with sickle cell disease.

## Measure Collection Name

Sickle Cell Disease Measures

## Submitter

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

## Developer

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

## Funding Source(s)

This work was funded by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) under the CHIPRA Pediatric Quality Measures Program Centers of Excellence grant number U18 HS020516.

## Composition of the Group that Developed the Measure

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Sickle Cell Disease Measure Developers:

Kevin J. Dombkowski, DrPH, MS, Research Associate Professor of Pediatrics, School of Medicine, University of Michigan  
C. Jason Wang, MD, PhD, Associate Professor of Pediatrics, Stanford School of Medicine  
Gary L. Freed, MD, MPH, Professor of Pediatrics, School of Medicine; Professor of Health Management and Policy, School of Public Health, University of Michigan  
Samir Ballas, MD, Professor, Division of Hematology, Thomas Jefferson University  
Mary E. Brown, President and Chief Executive Officer, Sickle Cell Disease Association, California  
George Buchanan, MD, Pediatric Hematologist, University of Texas Southwest Medical Center at Dallas  
Cathy Call, BSN, MSC, Senior Policy Analyst and Director for Health Quality Research, Altarum Institute  
J. Mitchell Harris, PhD, Director Research and Statistics, Children's Hospital Association (formerly NACHRI)  
Kevin Johnson, Professor and Vice Chair of Biomedical Informatics, Vanderbilt University  
Peter Lane, MD, Pediatric Hematologist-Oncologist, Children's Healthcare of Atlanta Pediatric Hospital  
Don Lighter, MD, MBA, FAAP, FACHE, Director, The Institute for Health Quality Research and Education  
Sue Moran, BSN, MPH, Director of the Bureau of Medicaid Program Operations and Quality Assurance,

Michigan Department of Community Health  
Suzette Oyeku, MD, Assistant Professor of Pediatrics, Albert Einstein College  
Lynnie Reid, Parent Representative  
Joseph Singer, MD, Vice President Clinical Affairs, HealthCore, Inc.  
Elliott Vichinsky, MD, Pediatric Hematology-Oncology, Children's Hospital and Research Center  
Winfred Wang, MD, Hematologist, St. Jude Children's Hospital

## Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

## Adaptation

This measure was not adapted from another source.

## Date of Most Current Version in NQMC

2013 Dec

## Measure Maintenance

Unspecified

## Date of Next Anticipated Revision

Unspecified

## Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in January 2016.

## Measure Availability

Source available from the [Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium \(Q-METRIC\) Web site](#) . [Support documents](#)  are also available.

For more information, contact Q-METRIC at 300 North Ingalls Street, Room 6C08, SPC 5456, Ann Arbor, MI 48109-5456; Phone: 734-232-0657; Fax: 734-764-2599.

## NQMC Status

This NQMC summary was completed by ECRI Institute on July 25, 2014. The information was verified by the measure developer on September 16, 2014.

The information was reaffirmed by the measure developer on January 7, 2016.

## Copyright Statement

This NQMC summary is based on the original measure, which is subject to the measure developer's copyright restrictions.

Inform Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) if users implement the measures in their health care settings.

## Production

### Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate antibiotic prophylaxis for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2013 Dec 13. 43 p. [15 references]

## Disclaimer

### NQMC Disclaimer

The National Quality Measures Clearinghouse<sup>®</sup> (NQMC) does not develop, produce, approve, or endorse the measures represented on this site.

All measures summarized by NQMC and hosted on our site are produced under the auspices of medical specialty societies, relevant professional associations, public and private organizations, other government agencies, health care organizations or plans, individuals, and similar entities.

Measures represented on the NQMC Web site are submitted by measure developers, and are screened solely to determine that they meet the [NQMC Inclusion Criteria](#).

NQMC, AHRQ, and its contractor ECRI Institute make no warranties concerning the content or its reliability and/or validity of the quality measures and related materials represented on this site. Moreover, the views and opinions of developers or authors of measures represented on this site do not necessarily state or reflect those of NQMC, AHRQ, or its contractor, ECRI Institute, and inclusion or hosting of measures in NQMC may not be used for advertising or commercial endorsement purposes.

Readers with questions regarding measure content are directed to contact the measure developer.